

DOCUMENT RESUME

ED 241 622

UD 023 372

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TITLE [Parental Rights versus Government Responsibility for Infant Medical Care.] Remarks before the American Jewish Congress, New York Metropolitan Council (January 29, 1984, New York, New York).
INSTITUTION Department of Justice, Washington, D.C. Civil Rights Div.
PUB DATE 29 Jan 84
NOTE 13p.; Remarks of the Assistant Attorney General, Civil Rights Division, U.S. Department of Justice.
PUB TYPE Viewpoints (120) -- Speeches/Conference Papers (150)
EDRS PRICE MF01/PC01 plus Postage.
DESCRIPTORS *Childrens Rights; *Civil Rights Legislation; *Disabilities; Equal Protection; Government Role; Hospitals; *Medical Services; *Neonates; Parent Child Relationship; *Parent Rights; State Legislation
IDENTIFIERS *Parental Consent for Minors

ABSTRACT

A recent ruling in the Baby Jane Doe case held that as parents are ultimately responsible for a child, and as in this case, the parents were not recipients of Federal assistance, neither they nor the hospital following their instructions to withhold treatment from their handicapped newborn are subject to Federal provisions about discrimination on the basis of handicap (Section 504 of the 1973 Rehabilitation Act). This argument is seriously flawed. Although our laws recognize that children's rights are generally best safeguarded by parents, these rights are independently protected by Federal constitutional and statutory guarantees. State child neglect and abuse laws also recognize that parents' and children's rights are not always coterminous and provide for governmental and judicial intervention in certain circumstances. The law extends these protections on an equal basis to "individuals" without reference to age, infirmity, or incapacity. Thus, a hospital cannot use the excuse of parental non-consent, but has a legal responsibility to initiate appropriate action to override parental authority in certain circumstances. Furthermore, a hospital and its staff can effectively discriminate against a handicapped child through the advice and information given to the parents concerning the child's condition and prognosis. Given this reality, Federal access to hospital records is the absolute minimum protection due to the handicapped infant under Section 504. (CMG)

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Department of Justice

ED241622

REMARKS

OF

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ASSISTANT ATTORNEY GENERAL
CIVIL RIGHTS DIVISION
U. S. DEPARTMENT OF JUSTICE

BEFORE

AMERICAN JEWISH CONGRESS
NEW YORK METROPOLITAN COUNCIL

SUNDAY, JANUARY 29, 1984
NEW YORK, NEW YORK

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I am pleased to be with you today and to participate in this important and timely policy conference on "Parental Rights Versus Government Responsibility for Infant Medical Care." Few issues are as difficult or as emotionally charged as the question of what medical measures ought to be taken to save the life of a newborn child who, irrespective of life-preserving medical treatment, is expected to be incurably handicapped in his or her future life.

In the first instance, the question poses a moral dilemma, to be analyzed and answered by each individual according to that individual's values and beliefs. But, as the title of today's conference reflects, the question also poses a broader issue of public policy -- a civil rights issue that, in the end, must be resolved through application of the community's shared values -- that is, by application of laws. It is to this dimension of the question I would like to address my remarks today.

Federal law prohibits recipients of federal financial assistance from discriminating against individuals on the basis of handicap in any federally-funded program. Under this law, Section 504 of the 1973 Rehabilitation Act, nourishment and medically beneficial treatment may not be withheld from handicapped infants solely because of their present or anticipated mental or physical impairments.

It has been suggested that federal inquiry into whether a hospital, as a recipient of federal financial assistance, has discriminated against a handicapped infant by failing to require the performance of life-preserving care or medical procedures must end if the infant's parents refuse to consent to such care or procedures. Indeed, that was the thrust of the district court opinion of Judge Wexler in the Baby Jane Doe case that is presently on appeal in the Second Circuit. As long as the hospital is following parental instructions in declining to perform the procedures in question -- so the theory goes -- the hospital cannot be guilty of any discrimination, since its staff cannot legally perform surgery or other medical procedures upon the child without parental consent. The parents, it is argued, are the only entities responsible for action determining whether the child receives the treatment or medical care in question - that is, by consenting or refusing consent. And, since they are not recipients of federal assistance, the parents are not subject to federal prohibitions against discriminatory behavior or decision-making.

This argument is, in my judgment, seriously flawed from a law enforcement point of view. It unrealistically absolves hospitals of all responsibility and effectively removes Government from its traditional civil rights enforcement role under Section 504. Let me expand on that observation.

It is, of course, true that the performance of a medical procedure upon a child ordinarily requires the consent of a parent or legal guardian. This is so because the law has long recognized the incapacity of children to make certain kinds of decisions for themselves, or to accurately assess their own best interest. The law presumes that parents have not only the capacity to recognize their children's best interests, but the desire to do whatever will best serve those interests. In general, this is an accurate and wise assumption. A parent can usually be depended upon to act in the child's best interests, to the best of the parent's ability to understand and promote them.

Yet, this is not always the case, and state laws generally recognize this unfortunate reality by providing for means of governmental and judicial intervention in cases of parental neglect or abuse of a child. This fact underscores the essential premises on which our laws regarding parent and child are based. Among those premises is the conviction that the individual rights and interests of children, which merit protection in their own right, are generally best assured and safeguarded by parents -- adults who are well situated to discern those interests and strongly motivated by love to pursue them. Moreover, because of the complex dynamics of family life and psychological needs of children for stability and certainty, the best interests of children are generally

served by affording parents substantial authority and autonomy in making decisions affecting their children.

But it is important to note that our law is distinctly not premised on a view that a child's rights and interests are necessarily coterminous with those of his or her parents. And a child's rights -- at least, federal rights -- are certainly not subordinate to or somehow dependent upon those of his parents. To the contrary, children, no less than adults, are independently protected by federal constitutional and statutory guaranties, including the full panoply of civil rights protections.

It is against this backdrop that we must consider the implications of parental consent or non-consent in a "Baby Doe" case. Under some circumstances, parental failure to permit life-preserving medical procedures from being performed on a child may constitute child abuse or neglect under state law. For example, consider a case where, for religious reasons, parents refuse to permit a blood transfusion necessary to save the life of an otherwise normal, healthy child injured in a car accident. Few would question the propriety of a hospital seeking to have such a parental decision overturned by another authority. In all probability, the hospital would seek the intervention of a court to remove the child temporarily from the parents' legal guardianship and authorize the needed transfusion, or would report to the local child

abuse and neglect prevention agency, thereby prompting possible government intervention. Indeed, under the laws of most states, the hospital would have a legal responsibility to take some action.

There is no meaningful distinction between this case and many of the cases of handicapped newborns - that is, no distinction except that, in my example, the child is otherwise normal and healthy with every promise of a full and vibrant life, while the "Baby Doe" infant has been born with a disability that portends a life that, in the eyes of some, will be more painful, perhaps much shorter, and certainly filled with monumental inconveniences for all the family.

Let no one misapprehend the significance of this difference. In most cases, it translates into two very different lifestyles - a difference in economic burden, in emotional strain, in responsibilities assumed and undertaken, and in just plain work.

But this reality, notwithstanding its potentially overwhelming consequences in some circumstances, is not one of which the law, or those charged with its enforcement, may properly take cognizance. For the law establishes basic rights and protections for "individuals" -- for "persons" -- terms that are not defined or limited with reference to age, infirmity, or incapacity.

One of these most basic rights is to enjoy the protection of the laws to an equal extent as other individuals in society. Can there be any doubt, then, that a child, no matter how young or how severely handicapped, has a claim of right to the protection of state laws prohibiting child abuse and neglect on an equal basis with any other child? Part of this protection lies in state law provisions aimed at third persons, such as medical professionals, charged with reporting responsibilities when confronted with instances of possible child abuse or neglect, and with the obligation to aid in the prevention of such conduct. Another part is lodged with the courts that are empowered to override parental decisions in certain situations.

It is thus not sufficient to use parental consent as an excuse for withholding recommended medical treatment. Even in the absence of the parents' consent to medical procedures necessary to save the life of a "Baby Doe," a hospital retains a responsibility to initiate appropriate action through child welfare agencies and, if need be, in the courts, to override parental authority -- in precisely the manner that it would proceed under my earlier hypothetical, where the parents denied consent for a blood transfusion needed by an injured but otherwise normal child.

This being the case, a parental decision to withhold consent to a medical procedure needed to save the life of

a handicapped newborn does not alone pretermite the opportunity for federal inquiry. The possibility still exists for the hospital to act discriminatorily towards that child. Its choices are, quite clearly, to respond to the parental decision with silent acquiescence, or to take action by seeking outside review of that decision by appropriate authorities. Silent acquiescence may well be proper in some situations, depending on the severity of the disability and available medical treatment for the infant's condition. But if the hospital's decision not to invoke outside intervention to override the parental decision is based solely on the fact that the child suffers from mental or physical handicaps, then this choice is discriminatory and legally prohibited in the context of federally-assisted hospital activities.

There is another reason that a parental decision to withhold consent to a medical procedure does not resolve the question of whether a hospital's federally-assisted activities are being carried out free from discrimination based on handicaps. A treating hospital and its staff can have an enormous influence upon the outcome of parental decision-making. As I observed earlier, parents can generally be expected to act in their children's best interests -- to the extent of their ability to understand and promote those interests. But to what extent can the parents of a severely handicapped newborn accurately assess their child's true circumstances? Their

assessment, of course, and whatever decisions they may make regarding medical care for their child, must necessarily be based on the information and advice provided to them by medical professionals. It would certainly be possible for a hospital to effectively discriminate against a handicapped child through the advice and information given to parents regarding their child's condition and prognosis.

I do not intend to suggest here that the substance of bona fide medical judgments is subject to governmental review or should be considered discriminatory because they communicate a negative prognosis. I do maintain, however, that protection of handicapped infants from invidious discrimination demands that bona fide medical judgments be the basis of treatment decisions, and not personal biases of involved medical personnel, or others, regarding "quality of life." And, under Section 504, the bona fides of the medical judgment on which parental decisions have been based may be an issue open to investigation by federal authorities.

Perhaps an example will help to illustrate the point. One of the most publicized cases of a handicapped "Baby Doe" was that of a Down's Syndrome child born in Bloomington, Indiana. The parents of that child refused to consent to surgery upon the child's esophagus, surgery without which the child could not receive life-sustaining nourishment. The obstetrician who first advised the parents as to their child's

condition and prognosis described Down's Syndrome children as in many cases "mere blobs." He told them that while most Down's Syndrome children could eventually learn to walk and talk, their speech generally consists of at best a single word -- that Down's Syndrome children are quite incapable of communicating what they feel and sense, and cannot attain even a minimally acceptable "quality of life."

This information can hardly be considered an expression of bona fide medical judgment. It represents a vast departure from any acceptable professional standard of accuracy in the presentation of well-established information and clinical experience. Yet, I think we can safely assume that this initial description of the child's future strongly influenced his parents in their decision to withhold consent to life-saving surgery. The child, after six agonizing days, died of starvation.

The point is that there are, indeed, instances in which hospital staffs who advise distraught parents are in fact responsible to a considerable degree for the decision to let an infant die. Given this reality, a hospital should not be able to raise parental non-consent as an impenetrable shield to all inquiry regarding the hospital's role in determining the treatment of an infant patient submitted to its care. As we assert in the Baby Jane Doe case in the Second Circuit -- and at this stage in the case this is all

that we assert -- access to hospital records should be allowed in order to permit the claim of discrimination to be investigated. That is, I submit, the absolute minimum protection that this handicapped infant is entitled to under Section 504.

In closing, I want to share with you part of one of the many letters I and the Attorney General have received from private citizens respecting the issue of treatment for handicapped newborns. A woman who now works with handicapped children wrote that she was diagnosed at birth as brain-damaged, and given a prognosis in terms of potential and quality of life similar to that which has been given to Baby Jane Doe, the New York child with spina bifida and other afflictions. This woman has taught for several years and is in the process of earning a second graduate degree. She had this to say:

The most crucial issue underlying this case is what value an individual life has. In our society, there is a strong tendency to value a person for what [he or she] can do; and the goals of child rearing, education, and training often center on eventual productivity. When such a value system is in force, people who cannot be very productive in the traditional sense of the term tend to be regarded as being less valuable, less important, and less deserving of the rights afforded to "productive people." Doctors are just as susceptible to adopting a productivity personal value perspective as anyone else, but a doctor's professional status does not make such a perspective more legitimate. The documents proclaiming rights in this country -- the Declaration of Independence, the Constitution of the United States, etc. -- do not specify that a person must be "productive" to have equal rights.

It is, I think, important that this observation be kept in mind in our deliberations on this most difficult issue. It is equally important to recognize -- as this letter and this woman's personal experiences illustrate -- that our predictions of human potentialities, even when based upon the best available medical information and advice, are far less than certain. By assuming facts of which we cannot possibly be certain, by too quickly stopping short in our inquiry as to human worth, and by not always fully appreciating that the full measure of legal and human rights belong as well to those infants born with the most severe of handicaps, we may, perhaps, succeed in simplifying some of our own tasks and responsibilities. But, it is certain that we will in that process lose much that is valuable in our society, and inexcusably compromise the integrity of our most cherished legal principles. It is, therefore, imperative, in my judgment, that the Government's efforts on behalf of the Baby Does in our society not be abandoned.

Thank you.